Predicting Psychosocial Outcomes Using a Brief Measure of Quality of Life in a Sample of People with Spinal Cord Injury

Bryan Kemp, PhD,[1] Dmitry Tsukerman, MS,[2] Jason Kahan, PhD,[3] and Rodney Adkins, PhD[3]

[1]University of Southern California, Keck School of Medicine, Los Angeles, California; [2]California State University, Fullerton, California; [3]Los Amigos Research and Education Institute, Downey, California

Background: Spinal cord injury (SCI) significantly impacts an individual's quality of life (QOL). A brief and subjective measure of QOL is necessary to monitor the progress and outcomes of SCI rehabilitation. **Objective:** To determine whether this measure of QOL was associated with clinically important physical and psychosocial outcomes in a sample of people with SCI, to determine how people with SCI scored on this measure of QOL, and to determine whether people with SCI scored differently than nondisabled individuals on the QOL scale. **Methods:** Participants were 134 people with SCI (65% male; 35% female) and 227 nondisabled people (35% male; 65% female). Participants were assessed on a number of psychosocial and physiological variables at a large urban university and rehabilitation center. Variables examined were QOL, life satisfaction, depression, social interaction, pain, fatigue, and level of functioning. **Results**: Participants with SCI reported more low QOL scores and fewer high QOL scores than the nondisabled group. For participants with SCI, QOL was positively related to life satisfaction and social interaction and negatively related to pain, fatigue, and depression. **Conclusions**: Participants with SCI scored lower on the QOL measure than those without a disability, although the difference was not clinically significant. QOL was unrelated to level of functioning; people may still experience a high QOL despite their physical limitations. Depression and social interaction were significantly related to QOL and should be secondary targets for intervention following SCI rehabilitation. **Key words**: *depression, disability, life satisfaction, pain, quality of life, social interaction, spinal cord injuries*

Quality of life (QOL) can be defined as the quality of a person's overall experiences of living. Individuals differ on what values they place on work, leisure activities, relationships with other people, intimacy with a spouse or partner, or participation in sports. Perhaps no other impairment impacts a person's QOL as much as a spinal cord injury (SCI).[1] After the medical and functional problems are addressed in rehabilitation, individuals begin to think about how they can regain much of their previous lifestyle and QOL. There are substantial barriers in the physical and social environments that stand in the way of higher QOL, including medical issues; difficulties in constructing a suitable home environment; and challenges in keeping the family together, supporting oneself, and dealing with the subtle and not-so-subtle attitudes of others.[2] These problems and barriers can result in psychological issues, the most common of which is depression.[3] It is not surprising that individuals find it difficult to regain a positive level of QOL after SCI.

Considering that there are approximately 270,000 people currently living with SCI in the United States, with 12,000 new cases of SCI each year,[4] the topic of QOL is important to the persons with SCI, their families, and to the clinicians who treat them. However, there is little agreement on the definition of QOL and therefore on its measurement. Most measures of QOL are either too long for clinicians to use in practice or are not measures of QOL itself, but rather are measures of life satisfaction, health status, or well-being. For example, The World Health Organization's[5] QOL measure, WHOQOL-BREF, is primarily a life satisfaction measure, and it takes more than 1 hour to administer. Even the SF-36,[6] which many people inaccurately accept and use as a measure of QOL, is actually a measure of health status, according to the author.

Corresponding author: Dmitry Tsukerman, Department of Psychology, California State University, Fullerton, PO Box 6846, Fullerton, CA 92834-6846; ; phone: 562-686-7819; e-mail: dtsukerman@fullerton.edu

Top Spinal Cord Inj Rehabil 2014;20(3):191–196

www.thomasland.com

doi: 10.1310/sci2003-191

Experts in both QOL and SCI, including Dijkers[7] and Tate,[8] have argued that there is a need for a subjective measure of QOL that can be used to monitor a person's progress of rehabilitation and as a measurable outcome of rehabilitation programs. Clinical practice requires brief measures that are reliable and valid and that can be incorporated into progress notes about the patient. This clinically oriented article addresses the issue of whether a brief measure of QOL can stand up to the rigors of scientific standards while still predicting clinically important outcomes of SCI and whether it is suitable for the practitioner as well as for persons with SCI.

This article addresses 3 objectives. The first objective was to determine whether this measure of QOL was associated with clinically important physical and psychosocial outcomes in a sample of people with SCI. The second objective was to determine how people with SCI scored on this measure of QOL. The third objective was to determine whether people with SCI scored differently than nondisabled individuals on a subjective, single-item QOL scale.

Methods

Participants

This study was conducted at both a university and a rehabilitation center in the Southern California area. This research included 134 people with SCI. The participants signed consent forms approved by the institutional review board of a major rehabilitation medical center and university. Both men (65%) and women (35%) were included. The participants were from 24 to 80 years old; the mean age was 48.8 (*SD* = 12.7). Approximately 40% of participants were from underserved populations, principally Hispanic and African American. Duration of SCI was from 1 to 65 years, with a mean of 24.8 years (*SD* = 13.3). The participants were paid $10. The participants came from the greater Southern California area and can best be described as a convenience sample. A comparison group of nondisabled individuals was recruited in a similar manner. Many of them were friends, family, neighbors, spouses, and children of people in the group with SCI. In addition, staff from the hospital and the university also volunteered. This group can be described as a convenience sample. Of the 227 nondisabled participants, 35% were male and 65% were female. The mean age was 59.3 years (*SD* = 17.0).

Measures

Quality of life

The measure of QOL[9] was a single item that asked the individual to rate his or her own QOL. The measure was a Likert-type scale ranging across 7 steps. The scale itself was shown on a piece of paper and measured 1 in. x 7 in. The low end of the scale was described as "Life is very distressing; it is hard to imagine how it could get much worse." The high end of the scale was indicated by "Great; it's hard to imagine how it could get much better." The mid-point was described as "so-so." No other steps on the scale were described. The person was read the instructions for the scale as follows: "Taking everything in your life into account, please indicate where you are by making an 'X' on the written scale or by telling me where you are." This measure underwent a separate test-retest reliability study with people who had an SCI (n = 50) and with nondisabled graduate students (n = 67) at a major university.[10] Over a 1-week interval, the people with SCI showed a reliability of .89 and the graduate students showed a reliability of .87.

Life satisfaction

Life satisfaction was assessed using a slightly modified form of the Satisfaction with Life Scale.[11] The scale was modified by eliminating 1 item (general health) that was assessed with a separate scale, leaving a total of 11 items. Each item was rated on a 4-point scale (from 1= *most dissatisfied* to 4 = *very satisfied*), and the average of all the items was taken as the final score.

Depression

Depression was measured by a 22-item scale first described by Kemp and Adams.[12] It was evaluated against psychiatric evaluations. Only a few physiological items were retained because

Table 1. Comparison of SCI and nondisabled samples on quality of life scores

Sample	1	2	3	4	5	6	7
SCI (%; *n*) *n* = 134 Mean = 5.2 *SD* = 1.1	0% (0)	2% (2)	5% (6)	19% (26)	30% (40)	38% (51)	7% (9)
Nondisabled (%; *n*) *n* = 227 Mean = 5.7 *SD* = 1.0	<1% (1)	1% (2)	1% (3)	9% (20)	24% (54)	47% (106)	18% (41)

people with a disability often have these kinds of problems and the authors wanted to decrease false positives. Scores of 5 and below were considered normal, scores of 6 to 10 indicated mild-to-moderate depression, and scores of 11 or higher indicated a major depressive episode as judged by the psychiatric evaluations.

Social interaction

The 16-item social interaction inventory was developed by Kahan[13] as a measure of how much the person interacted with other people and/or got out of the house to conduct community activities. The test-retest reliability was .87, and the validity of this measure has been supported across several studies.[14]

Pain

Participants rated the severity of their pain on a 4-point scale (from 0 = *no pain* to 3 = *very severe pain).*

Fatigue

Fatigue was measured using the Fatigue Severity subscale.[15] The score was comprised of participants' average ratings on 11 items measuring common causes of fatigue. Each of the 11 items was rated on a 7-point scale (from 1= *low* to 7 = *high*).

Level of functioning

Level of functioning (degree of disability) was measured by taking a count of the number of activities of daily living tasks plus the number of instrumental activities of daily living tasks from the Older Adults Resource and Services Program[16] on which the person rated that he or she was independent. Total scores range from 0 to 14.

Results

The frequency distributions for each level of QOL were as follows: 1 = 0%; 2 = 2%; 3 = 5%; 4 = 19%; 5 = 30%; 6 = 38%; 7 = 7%. The mean QOL score was 5.2 (*SD* = 1.1). The scores for each level of QOL for the 227 nondisabled individuals described earlier are presented in **Table 1**, along with the scores for the SCI group. To make meaningful comparisons, we divided scores into 3 levels for both groups. The distribution was as follows: SCI group, low (n = 34), average (n = 40), and high (n = 60); nondisabled group, low (n = 26), average (n = 54), and high (n = 147). We created the groups by taking the mean QOL score for the SCI group and assigning those scoring 1 *SD* or more above the mean to the high QOL group and those scoring 1 *SD* below the mean to the low QOL group. The nondisabled group was then divided at the same points as the disabled group. The low group included scores from 1 to 4, the average group reflected a score of 5, and the high group included scores of 6 and 7. There was a mean difference in QOL scores between the 2 groups, with the nondisabled group (M = 5.7, SD = 1.0) having a higher average QOL score than the SCI group (M = 5.2, SD = 1.1), t (359) = 4.28, $P < .001$. We then conducted a chi-square analysis between the groups. The results showed significance at

Table 2. Intercorrelation matrix for quality of life variables

	1	2	3	4	5	6	7	8	9	10
1. Quality of life	–									
2. Age	.07	–								
3. Education	.11	-.02	–							
4. Duration	.13	.75***	.15	–						
5. Level of functioning	.08	-.14	.01	-.06	–					
6. Pain	-.20*	.16	.21*	.12	-.18*	–				
7. Fatigue	-.20*	.06	.09	.13	-.09	.21*	–			
8. Depression	-.56***	.03	-.28**	.01	-.13	.29**	.46***	–		
9. Life satisfaction	.61***	.07	.01	.07	.02	-.25**	-.33***	-.65***	–	
10. Social interaction	.48***	-.12	.18*	-.14	.14	-.08	-.16	-.36***	.37***	–

Note: $N = 133$.
*$P < .05$. **$P < .01$. ***$P < .001$.

the .001 level, $\chi^2(2, N = 361) = 16.88$. Further examination indicated that the nondisabled group had a higher percentage of people scoring in the high QOL level, whereas the SCI group had a higher percentage scoring in the low QOL level.

Correlations among all variables were examined and are shown in **Table 2.** QOL was positively related to life satisfaction ($r = .61$) and social interaction ($r = .48$). QOL was negatively related to pain (r = -.20), fatigue ($r = -.20$), and depression ($r = -.56$). There were no significant relationships between QOL and age, years of education, duration of disability, or level of functioning.

We next examined possible QOL group (ie, low, average, high) differences in the key demographic variables of age, gender, years of education, and duration of impairment. There were no significant differences on any of these variables except for education. For education, the low QOL group had significantly fewer years of education than the average QOL group, and no differences were found between the average and the high QOL groups. The mean years of education for the QOL groups were as follows: low QOL = 13.47; average QOL = 15.30; high QOL = 14.68. The results of the analyses of variance (ANOVAs) are presented in **Table 3** grouped by physical (level of functioning, pain, fatigue) and psychosocial (social interaction, depression, life satisfaction) variables. Level of functioning was nonsignificant, whereas both pain and fatigue were significant ($P < .05$). Participants in the high QOL group experienced less pain ($M = 1.27$) than either the average ($M = 1.8$) or low groups ($M = 1.68$). Participants in the high QOL group also had significantly less fatigue ($M = 1.63$) than participants in either the average ($M = 2.81$) or low ($M = 2.78$) groups. Social interaction, depression, and life satisfaction were all significant at $P < .001$, and all pair-wise comparisons were significant.

Discussion

In terms of the objectives to determine how people with SCI score on the QOL scale and whether these scores differ from people without SCI, the results show that there were significant differences between the 2 samples. People with SCI scored lower on the measure of QOL than did the nondisabled individuals. Although the difference was significant, it was not very great in terms of actual meaning. There was only a half-point difference between the 2 groups; the sample with SCI had a mean QOL score of 5.2, whereas the nondisabled sample had a mean of 5.7. Even though the nondisabled sample had more high scores than did the SCI sample, it is noteworthy that many people with SCI also scored in the high range. The biggest difference, however, was the number of people scoring in the low range on the

Table 3. Results of the analysis of variance grouped by physical and psychological variables

	Total sample ($N = 134$)	Low QOL group ($n = 34$)	Average QOL group ($n = 40$)	High QOL group ($n = 60$)	
Variables	**Mean (*SD*)**	**Mean**	**Mean**	**Mean**	***F* values**[a]
Age	48.79 (12.71)	47.88	47.55	50.13	.61
Education, years	14.56 (3.10)	13.47	15.30	14.68	3.40*
Duration	24.83 (13.27)	21.21	24.98	26.78	1.95
Level of functioning	6.64 (.00)	6.79	5.88	7.07	1.31
Pain	1.53 (1.12)	1.68	1.80	1.27	3.25*
Fatigue	2.28 (2.28)	2.78	2.81	1.63	4.54*
Social interaction	36.88 (15.53)	27.38	35.62	43.08	13.40***
Depression	4.98 (4.58)	8.5	5.23	2.82	22.07***
Life satisfaction	3.01 (.60)	2.53	2.93	3.33	28.61***

Note: QOL = quality of life.
[a]*df* are (2, 131), except for social interaction, which are (2, 130).
*$P < .05$. ***$P < .001$.

QOL scale. Approximately 25% of the sample with SCI scored in the low QOL range, compared to only 11% for the nondisabled sample.

Approximately two-thirds of the people with SCI who scored low on the QOL measure also scored high on our measure of depression – well above the cutoff for major depression. Depression serves as a barrier to higher QOL. If persons with SCI received individual or group treatment for depression, many of them would be able to achieve a higher QOL. Kahan and colleagues[14] showed that when depression was treated in a sample of people with SCI, their QOL increased. In addition to depression, other issues also contribute to low QOL, including frequent medical problems, a loss of friendships, and worries about the future.

The overriding objective of this research was to determine whether a brief measure of QOL (ie, less than 1 minute to administer) could be used to identify problems that patients and clients may be having. An examination of **Table 2** (correlations matrix) and the results of the individual ANOVAs show that the important outcomes of pain, fatigue, depression, social interaction, and life satisfaction were all significantly related to scores on the brief QOL measure. Therefore, a clinician could include this measure in the screening of patients, because it would likely suggest other major problems as well.

When correlations between raw QOL and other variable scores were examined, the relationship between QOL and education was nonsignificant. However, when QOL scores were grouped into low, average, and high, a significant difference emerged: Participants with average and high QOL had significantly more years of education than the low QOL group, but the average and high groups did not differ from each other. It is noteworthy that the measure of level of functioning (ie, degree of disability) did not correlate with QOL. This means that QOL can be high, or at least average, regardless of a person's level of functioning or level of injury. This finding is consistent with previous research.[17] Clients with SCI should be made aware that they can achieve a suitable level of QOL with appropriate effort and guidance.

This measure is entirely subjective and the score is determined solely by the individual with SCI. Other than the 2 anchoring statements, the individual is left to determine his or her own QOL. Because it has already been shown that ratings of this measure are reliable, this measure should be taken as an honest statement of how the individual feels about his or her life at that time.

The 2 psychosocial variables that should be given the most clinical attention are depression (which we have already discussed) and level of social interaction (the person's involvement in social or community activities). We have found that persons with SCI have many concerns and much anxiety about increasing the amount of their

social involvement. These concerns often stem from unrealistic beliefs, such as fears that other people would make disparaging comments about them or that they would not fit into activities with nondisabled people. Counseling is often needed to help dispel these inaccurate beliefs about participating in the community.

There are several limitations of the study. First, the sample was only from the Southern California area, therefore these results may not hold true for people living in other areas. This study was also conducted using a convenience sample, rather than a randomized or matched design. Therefore, the conclusions are limited to this sample. These data were collected using primarily paper and pencil measures, so there is a need to try them out in the clinical setting. Future research should also be conducted on randomized or stratified samples.

Acknowledgments

Drs. Kemp, Adkins, and Kahan received grants from the National Institute on Disability and Rehabilitation Research during the conduct of the study. Mr. Tsukerman has no conflicts of interest to report.

REFERENCES

1. Duggan CH, Dijkers M. Quality of life after spinal cord injury: A qualitative study. *Rehabil Psychol.* 2001;46:3-27.
2. Craig A, Tran Y, Middleton J. Psychological morbidity and spinal cord injury: A systematic review. *Spinal Cord.* 2009;47:108–114.
3. Arango-Lasprilla J, Ketchum JM, Starkweather A, Nicholls E, Wilk AR. Factors predicting depression among persons with spinal cord injury 1 to 5 years post injury. *NeuroRehabilitation.* 2011;29:9-21.
4. National SCI Statistical Center. Spinal cord injury facts and figures at a glance. 2012. https://www.nscisc.uab.edu. Accessed February 27, 2014.
5. WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med.* 1998;28:551-558.
6. Ware JE. *SF-36 Health Survey: Manual and Interpretation Guide.* Boston, MA; Nimrod Press; 1993.
7. Dijkers MP. Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *J Rehabil Res Dev.* 2005;42(3):87-110.
8. Tate, DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. *Arch Phys Med Rehabil.* 2002;83(12):S18-25.
9. Kemp BJ, Adkins R. *The Subjective Quality of Life Scale.* Downey, CA and Los Angeles, CA: Los Amigos Research and Education Institute, University of Southern California; 2010.
10. Kemp B, Adkins RH, Mitchell J, Kahan J, Williams BR, Wilson DJ. *Final Report of the Rehabilitation Research and Training Center on Aging with a Physical Impairment.* Downey, CA and Los Angeles, CA: Los Amigos Research and Education Institute, University of Southern California; 2010.
11. Diener E, Emmons R, Larsen R, Griffin S. The Satisfaction with Life Scale. *J Pers Assess.* 1985;49:71-75.
12. Kemp B, Adams B. The older adult health and mood questionnaire: A measure of geriatric depressive disorder. *J Geriatr Psychiatry Neurol.*1995;8:162-167.
13. Kahan J, Kemp B, Bateham D, Mitchell J, Adkins RH. The Social Interaction Inventory: Development, reliability, and validity. In Kemp B, Adkins RH, Mitchell J, et al, eds. *Final Report of the Rehabilitation Research and Training Center on Aging with Physical Impairments.* Downey, CA and Los Angeles, CA: Los Amigos Research and Education Institute, University of Southern California; 2010.
14. Kahan JS, Mitchell JM, Kemp BJ, Adkins RH. The results of a 6-month treatment for depression on symptoms, life satisfaction, and community activities among individuals aging with a disability. *Rehabil Psychol.* 2006;51:13-22.
15. Schwartz J, Jandorf L, Krupp L. The measurement of fatigue: A new instrument. *J Psychometric Res.* 1993;17:753-762.
16. Fillenbaum GG. *Multidimensional Functional Assessment of Older Adults.* Hillsdale NJ: Lawrence Erlbaum; 1988.
17. Dijkers M. Quality of life after spinal cord injury: A meta analysis of the effects of disablement components. *Spinal Cord.* 1997;35:829-840.